



**Designing Post-Diagnostic Support
with People with Dementia**

Summary Report | December 2020



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Introduction

This summary report describes the findings of the first phase of an improvement project to deliver a peer to peer support intervention for people in the early stages of their dementia journey, facilitated by Occupational Therapists in Scotland.

Background and Policy

Dementia remains a priority for Scottish Government with a commitment that all people newly diagnosed with dementia will receive appropriate support following diagnosis, with that support being either the current model of post-diagnostic support, based on the 5 pillar model, Alzheimer Scotland, or care coordination, based on the 8 Pillars Model of Integrated Community Support.

Connecting People, Connecting Support (Alzheimer Scotland 2017, 2020) is the national framework for transforming the contribution of Allied Health Professionals (AHPs) to supporting people living with dementia and those who support them and a key commitment in Scotland's dementia strategies. Its aspiration is that people have better access to AHPs regardless of age or place of residence, from pre-diagnosis to diagnosis and throughout their illness. The four principles and ambitions for change in Connecting People, Connecting Support (CPCS) drive the transformation of AHP services to meet the needs of people living with dementia and those who support them to provide accessible and condition specific signposting to help, advice and rehabilitation. This ensures people get the right AHP support, at the right time, and in the right setting.

The developing evidence on the benefits of AHP early interventions, supported self-management and rehabilitation on helping people to live well with dementia is overwhelming. It is therefore imperative that AHPs develop and adopt models of practice based on the evidence and which reflect greater use of self-management, technology-based, co-created and partnership approaches. In addition to this, there are obvious benefits to getting timely access to good quality post-diagnostic support delivered by AHPs.

About Journeying Through Dementia

Journeying through Dementia is an occupation-based group programme that aims to support people at an early stage of their dementia journey to engage in meaningful activities and maintain community connectedness.

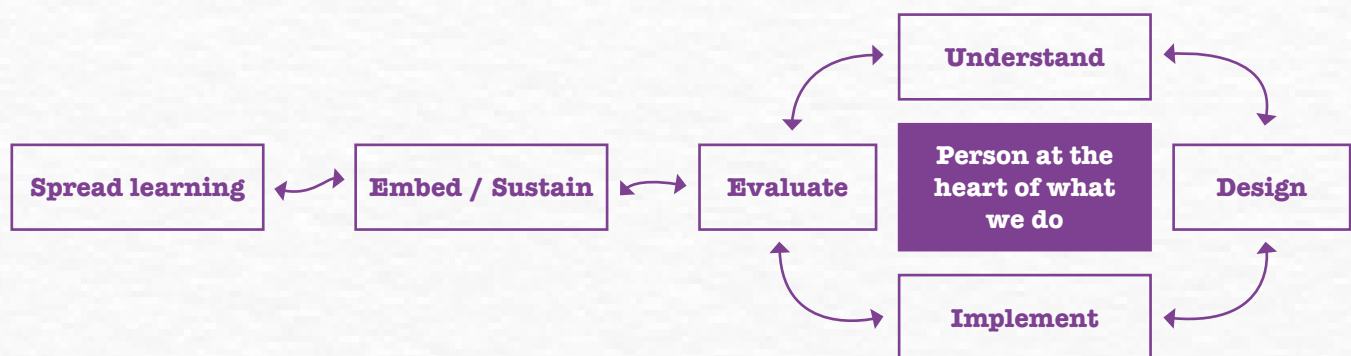
The programme was developed in partnership with people with dementia who spoke of the value they attached to continued participation in everyday occupations and in new learning. Throughout all the co-creation activities, people with dementia were clear that they wanted to have the opportunity to access groups that did not just talk about the diagnosis but that offered practical advice and support of how to continue to live well with the condition.

Journeying through Dementia is underpinned by the premise that there is a relationship between the activities we participate in and health and wellbeing. The aim of the program is to promote continued engagement in meaningful activity through equipping individuals with the knowledge, skills and understanding of ways to continue to do the things they enjoy for as long as possible. The importance of this cannot be underestimated.

Implementation and integration of Journeying through Dementia within the two demonstrator sites in Scotland has been underpinned by an improvement approach that aims to fully realise the impact of the ambitions across health, social care and partner organisations. A core component of the improvement project was the use of a Framework for Planned Improvement underpinned by a 'rapid cycle change' (Plan, Do, Study, Act) approach, the model focuses on three key questions:

- **What are we trying to accomplish?**
- **How will we know that a change is an improvement?**
- **What changes can we make that will result in an improvement?**

This enables us to review the work on an ongoing basis and respond to local services, local population and local occupational therapists, whilst also delivering an evidence based post diagnostic intervention.



Source: Adapted from work originally developed by Healthcare Improvement Scotland.

Participant Experience

71% of participants reported improved quality of life (QoL-AD)

In order to record the experience of the people in the group, the Occupational Therapists as facilitators posed four questions at the end of each group session and recorded and collated the responses. These questions were designed in order to illicit information relating to the participants experience of the session including what they found to be of benefit and of use, and anything they may have changed.

Thematic analysis was used to examine the information gathered and three themes were identified which reflected the experience of the participants within the group. This was then mapped back to occupation and the Person - Environment - Occupation Model of Occupational Performance (Law et al 1996) used to highlight the findings.

Person

Within the model the person is presented as “a dynamic, motivated and ever-developing being, constantly interacting with the environment” (Law et al., 1996, p.17). The model views the person holistically, recognising that each person “brings a set of attributes (performance components) and life experiences to bear on the transaction described as occupational performance, including self-concept, personality style, cultural background and personal competencies.” (Law et al., 1996, p.16). Journeying through Dementia takes a strengths-based approach where participants abilities are seen as key resources positioning the individuals very much as the experts at managing their condition. Facilitators aimed to guide the discussion, ensuring everyone’s voice was heard whilst also encouraging participants to use their own resourcefulness and appreciate the resources of others within the group. People taking part in the programme spoke openly of their experience within the group, sharing their thoughts and experiences and the impact the programme was having on their engagement in meaningful activities:

“It takes me beyond bumbling through.”

“The more you do the more you can do”

“I feel more confident”

“I have new friends I don’t think I will ever forget.”

“When I go home from here, I feel better.”

“I really enjoy myself.”

“I love coming along and getting to know others.”

“It’s been a really super day.”

Environment

Law et al (1996) offer a broad definition of the environment which “gives equal importance to the cultural, socio-economic, institutional, physical and social considerations of the environment.” (p.16), recognising that all these aspects shape and are shaped by the person. The facilitators strived to create an environment which was a safe space for people to openly share their thoughts, feelings and experiences of living with dementia and the challenges faced when engaging in valued occupations. Participants appeared to value the opportunity for open communication and frequently commented on this element of the group within the feedback:

“Comfortable sharing what we do”

“No judgement”

“Being around people that understand what I am going through”

“Saying what you like, and don’t have to worry about what you say.”

This was supported by the physical and social environments which were carefully selected and shaped by the group facilitators where possible, and any feedback relating to suggestions for improvement e.g. **“more pens for next week”** were taken on board.

“I feel we’re helping one another being on the same wavelength”.

“I feel very comfortable and feel I can speak openly.” ... “Relaxed atmosphere”

Occupation

This aspect of the model considers what people do within their environments and proposes three elements – activity, task and occupation - which are “defined discreetly but presented together to emphasise the close relationship” (Law et al., 1996, p.16). Law et al. further defined occupations as “those clusters of activities and tasks in which the person engages in order to meet his/her intrinsic needs for self-maintenance, expression and fulfilment. These are carried out within the context of individual roles and multiple environments.” (p.16). The group participants repeatedly commented on the value of the conversations and sharing of knowledge and experience throughout the course of the group interventions. Feedback suggests they found sharing and talking with others enjoyable but also reported it was useful:

“Everyone sharing their stories.” ... “Memory strategies discussed.”

“Content discussed provided clarity and cleared things in my head”

Journeying through Dementia is underpinned by the premise that there is a relationship between the activities we participate in and health and wellbeing, as such emphasis is further placed on ‘doing’ and the participants’ feedback frequently made reference to the activity undertaken within the group session. Participants often commented that the information and knowledge gained through the activity was the one thing they would take away from the session and commented positively on specific content of the sessions including the importance of routine and the introduction to the memory maintenance list, as well as fire safety and environmental information.

“Highlighted things I probably knew already but didn’t realise.”

“Taking a step back, think, re-evaluate can I change the way I do things”

“Understanding Dementia more.” ... “When I go home from here I do more.”

What Next?

This initial phase of work has successfully demonstrated that Occupational Therapy can help to improve quality of life for people living with dementia, utilising Journeying through Dementia as an evidence-based intervention, to support people to manage their own health and wellbeing. Funding has been secured from The Alliance self-management fund to support phase II however plans to spread the project to a further seven sites have been modified in response to the impact of Covid-19. An [online resource](#) has been developed which will be integrated into the project going forward, and a blended method of delivery is anticipated that includes digital platforms and greater use of printed resources that can be sent to people’s homes to ensure there is no exclusion from the programme due to access to technology. Future delivery will continue to consider the aim of supporting the rights-based values of the work and the key principles of the intervention components.



Bridgetta Menton & Emma Ingram - NHS Grampian



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We would like to dedicate this report to Bridgetta Menton, a dedicated, inspiring and motivated occupational therapist who was an integral part of the start of this project in Scotland.

References

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